

MORTALITY SPECIAL INCIDENTS

Semi-Annual Report Submitted to the
California Department of Developmental Services

JULY – DECEMBER 2009

Acumen, LLC

Acumen, LLC

500 Airport Blvd., Suite 365

Burlingame, CA 94010

INTRODUCTION AND BACKGROUND

This report summarizes mortality rates between July and December 2009 for DDS consumers living in the community. It compares mortality rates across recent years and identifies months in which mortality rates were unusually high.

DDS can use this report to track mortality rates over time and monitor the effectiveness of risk management activities.

As one element of risk management and quality assurance, the California Department of Developmental Services (DDS) and California's network of regional centers monitor the occurrence of adverse events, captured through Special Incident Reports (SIRs), to identify trends and develop strategies to prevent and mitigate risks. As required by Title 17, Section 54327 of the California Code of Regulations, vendors and long-term health care facilities report occurrences of suspected abuse, suspected neglect, injury requiring medical attention, unplanned hospitalization, and missing persons, if they occur when a consumer is receiving services funded by a regional center (under vendored care). In addition, *any occurrence* of consumer mortality or a consumer being the victim of a crime must be reported whether or not it occurred while the consumer was under vendored care. Acumen develops this report along with several others under a risk management contract with DDS.

This report summarizes mortality rates for DDS consumers between July and December 2009. The two main goals of this report are:

1. Update time trends in mortality rates from our earlier reports to include data through December 2009. DDS can use this report

to observe long term trends in statewide mortality rates, comparing the most recent six-month period to previous six-month periods.

2. Identify months in which statewide mortality rates were unusually high. For those months showing a statewide spike in mortality rates, we analyze the incident reports associated with the spike. By doing so, we can detect patterns that may lead to strategies to prevent similar events in the future. There were no reported spikes in the most recent six-month period (Jul-Dec 2009).

The rates and graphs presented in this report were constructed using data from the SIR System since 2002. These data are augmented with three additional data sources maintained by DDS:

1. The Client Master File (CMF)
2. The Client Development Evaluation Report (CDER), and
3. The Early Start Report (ESR).

This report presents findings based on statistical analyses that measure a consumer's risk of experiencing a special incident. Further details are found at the bottom of each subsequent page.

Unadjusted mortality rates decreased compared to last period, but were greater than rates from the same period last year.

Table 1: Reported Deaths for DDS Consumers
DDS Consumers, July-December 2009 Compared to Previous Periods

	Jul-Dec 2008 (Last Year)	Jan-Jun 2009 (Last Period)	Jul-Dec 2009 (This Period)
Number of Consumers	195,104	195,664	194,293
Number of Reported Deaths	739	796	768
Deaths per 1000 Consumers	3.79	4.07	3.95

Key Findings:



- Between July and December 2009, the number of deaths per 1000 consumers was 3% lower than it was during the previous six-month period.
- Mortality rates are typically lower during summer months. We have observed summer decreases in statewide mortality rates during each of the past four years.
- Compared to the same period last year (Jul-Dec 2008), the number of deaths per 1000 consumers increased by 4%. This increase is not statistically significant, and no follow-up activities are planned.

More About These Data

This report summarizes mortality rates for consumers living in the community (i.e. consumers receiving services from a regional center who do not reside in a Developmental Center or state-operated facility).

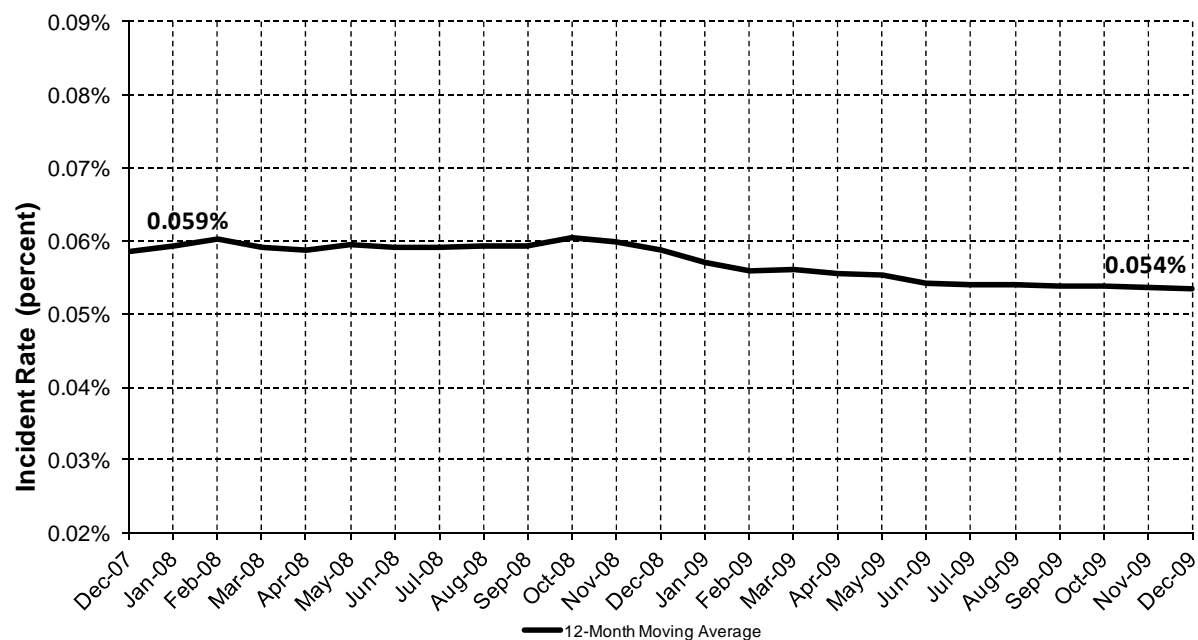
Number of Consumers refers to the average number of consumers served by regional centers in each month during the six-month period. Note that this total is less than the number of consumers ever served by regional centers during the six-month period.

Deaths per 1000 Consumers is calculated by dividing the number of reported deaths by the number of consumers, multiplied by 1000.

The data used to generate this report were provided to Acumen in February 2010. Although all deaths are reportable as special incidents, it may take time for deaths among consumers not under vendored care to be reported to the regional centers by parents/guardians. For this reason, it is common that additional mortality incidents are entered into the SIR system over time. Thus, the number of reported deaths for the most recent period may rise slightly as additional mortality data are reported to DDS.

Controlling for consumer characteristics, statewide mortality rates have declined since December 2007.

Figure 1: Mortality Incidents, Statewide Case-Mix Adjusted Monthly Trend
DDS Consumers since December 2007



Key Findings:

- The trend in statewide average monthly mortality rates has decreased over the past two years, from 0.059% in December 2007 to 0.054% in December 2009.
- Much of this decrease was concentrated in FY 2008-2009, as mortality rates in the most recent six-month period remained relatively constant.

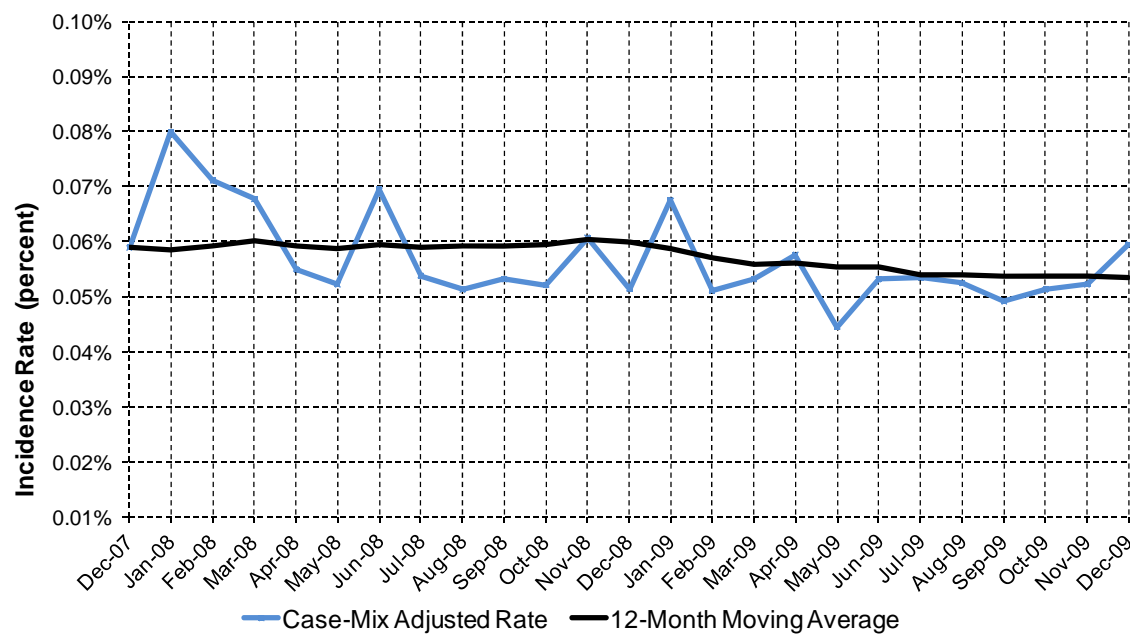
More About These Data

The line in Figure 1 represents a 12-month moving average for all DDS consumers. It is calculated by taking an average of statewide mortality rates from the most recent 12-month period.

The line in Figure 1 also accounts for the differences in the characteristics of the consumer population over time. This approach, called “case-mix adjustment,” controls for consumer characteristics and removes these effects from the calculated trend. For example, the share of the population over the age of 65 might increase, which would cause mortality rates to increase.

Mortality rates during the most recent six-month period were below the long-term average in all months except December.

Figure 2: Statewide Mortality Rates, DDS Consumers
Case-Mix Adjusted Monthly Rates since December 2007



Key Findings:

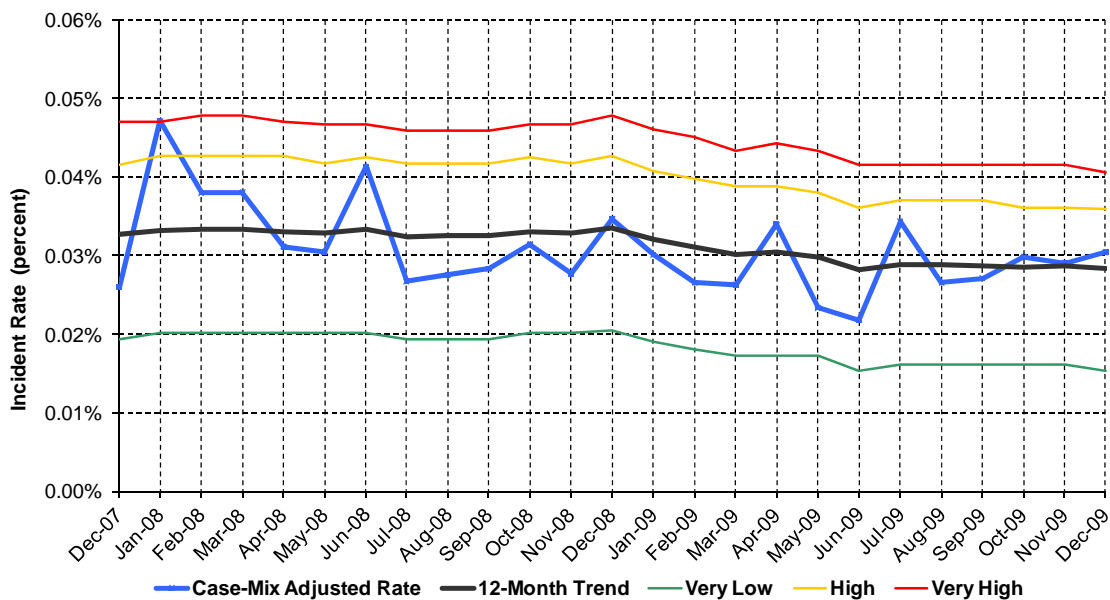
- Except in December, mortality rates in the most recent six-month period (blue line) were below the long-term average (black line).
- As noted on page 2, mortality rates are typically lower during summer months.

More About These Data

The line in Figure 2 is case-mix adjusted, accounting for changes in the consumer population. See the “More About These Data” section on page 3 for further details.

For the in-home population, mortality rates remained near the long-term average from July to December 2009.

Figure 3: Statewide Mortality Rates, In-home Consumers
Case-Mix Adjusted Monthly Rates since December 2007



Key Findings:



- Mortality rates for the in-home population were generally near the long-term average between July and December 2009.
- July 2009 saw an increase in mortality rates. However, this rate did not cross the “high” threshold, meaning the increase was not statistically significant, and no follow-up activities are planned. (See More About These Data below for additional details.)

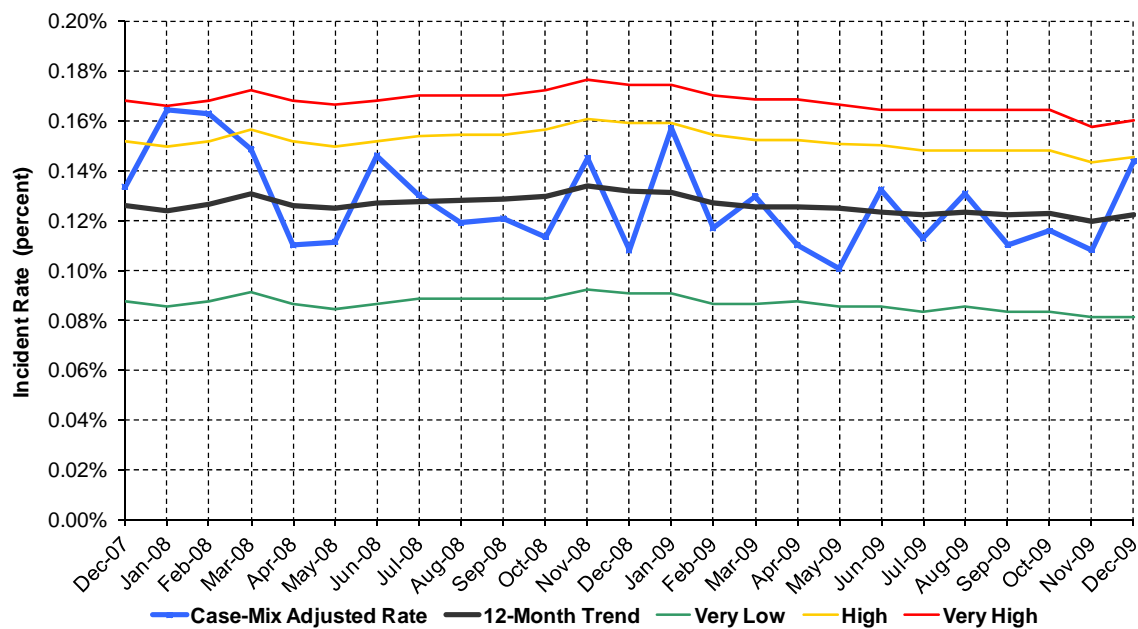
More About These Data

In-home Consumers are defined as individuals residing in their own home or the home of a parent, extended family member, or guardian, and who do not receive licensed residential services, Supported Living Services, or Independent Living Services.

This graph identifies mortality incident rates that are unusually high and therefore classified as a “spike.” For example, a rate that rises above the yellow line in a given month probably did *not* occur due to chance, since this will occur randomly in only one month out of twenty (less than 5% of the time). A rate that rises above the red line in a given month will occur randomly less than 1% of the time. Rates above the red or yellow lines, therefore, are very unlikely to be chance events and are classified as “spikes.”

For the out-of-home population, mortality rates dipped in autumn months, following a trend seen in previous years.

Figure 4: Statewide Mortality Rates, Out-of-home Consumers
Case-Mix Adjusted Monthly Rates since December 2007



Key Findings:



- As with the in-home population, mortality rates for the out-of-home population were near the long-term average between July and December 2009.
- December 2009 saw an increase in mortality rates, but this rate was not statistically significant as it did not cross the “high” threshold.

Follow-Up Activities:

- There were no statistically significant spikes in the most recent six-month period, so no follow-up activities are planned.

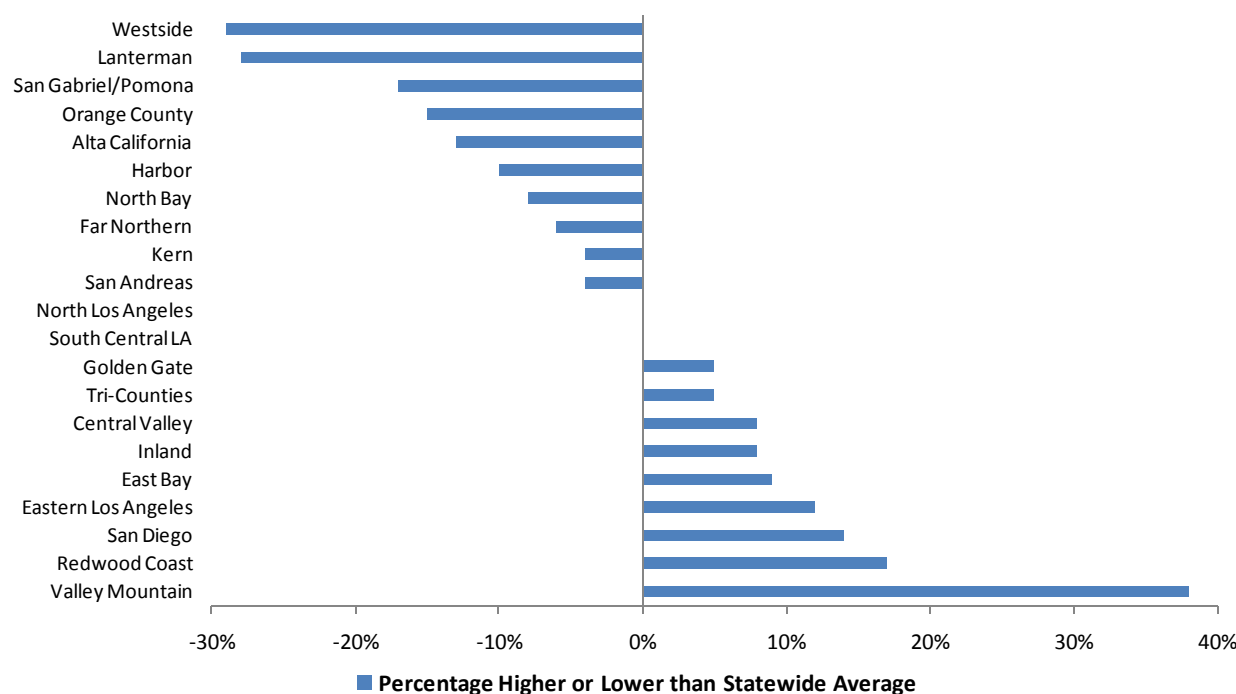
More About These Data

Out-of-home Consumers are defined as individuals residing in community settings such as licensed residential services, Family Home Agency (FHA), Supported Living Services (SLS), or Independent Living Services (ILS).

The yellow line in this graph identifies whether a rate is unusually high. This may occur randomly in only one month out of twenty (less than 5% of the time). A rate that rises above the red line in a given month may occur randomly in one month out of one hundred (less than 1% of the time). Rates above the red or yellow lines, therefore, are very unlikely to be chance events.

Among the 21 regional centers, Lanterman and Westside had the lowest mortality rates, while Valley Mountain had the highest.

Table 2: Mortality Rates by Regional Center Compared to Statewide Average
December 2008 – December 2009



Key Findings:

- Last year, Westside and Lanterman Regional Centers had the lowest mortality rates, at 29% and 28% below the statewide average, respectively.
- Valley Mountain Regional Center (VMRC) had the highest mortality rates, at 38% above the statewide average.

Follow-Up Activities:

- VMRC mortality rates, although they were highest among the regional centers in 2009, did not represent a statistically significant spike in any quarter and thus did not require a reporting back response. However, Acumen performed additional data analysis and descriptive statistics on VMRC’s 2009 deaths, finding no unusual trends. Acumen will perform additional review of these deaths as part of a broader review of mortality SIRs.

More About These Data

The percentages above are case-mix adjusted, meaning that they account for differences in the characteristics of the consumer population over time. See Page 3 for more details.

Breaking rates down by age and residence, mortality rates increased for most categories of consumers.

Table 3: Breakdown of Reported Deaths by Age and Residence Type
DDS Consumers, Jul-Dec 2009 Compared to Same Period Last Year

	Share of Consumers	Number of Deaths	Deaths /1000 Jul-Dec 2009	Change from Jul-Dec 2008
Age				
3 to 13	30%	61	1.0	-1%
14 to 21	21%	73	1.8	+34%
22 to 31	17%	81	2.4	+1%
32 to 41	11%	72	3.4	+3%
42 to 51	11%	122	5.9	+6%
52 to 61	7%	157	11.8	-2%
62+	3%	179	28.4	+5%
Residency Type				
Home	71%	257	1.8	+3%
Community Care	12%	198	8.5	+34%
ILS/SLS	10%	75	3.7	-16%
SNF/ICF	4%	194	23.3	+8%
Other	2%	21	5.8	-33%

Key Findings:

- Compared to last year, raw mortality rates increased in all age categories except consumers aged 3-13 and 52-61. Likewise, rates increased in all residence categories except for consumers living in ILS/SLS and Other.
- The 34% increase among consumers aged 14-21 reflects an unusually low rate in 2008. No follow-up activities are planned regarding this increase.

Follow-Up Activities:

- The 34% increase among consumers in Community Care reflects a rate that is higher than historical averages. Acumen will conduct a review of mortality SIRs to determine whether there are any systemic issues that require mitigation activities. (See page 10 for details on additional follow-up measures.)

More About These Data

The rates shown above are raw rates and do not account for changes in consumer characteristics. Community Care: Settings such as a Community Care Facilities (CCF) and other community settings, not including home of a family member or guardian, ILS/SLS, and SNF/ICF. ILS/SLS: Independent Living Setting or Supported Living Setting. SNF/ICF: Skilled Nursing Facility or Intermediate Care Facility. ICF includes ICF/Developmentally Disabled, ICF/Developmentally Disabled-Habilitation, and ICF/Developmentally Disabled-Nursing. Other: Settings such as hospitals, community treatment facilities, rehabilitation centers, psychiatric treatment centers, and correctional institutions.

Breaking rates down by diagnosis, mortality rates increased 72% compared to last year for consumers with autism.

Table 4: Breakdown of Reported Deaths by Diagnosis
DDS Consumers, Jul-Dec 2009 Compared to Same Period Last Year

	Share of Consumers	Number of Deaths	Deaths /1000 Jul-Dec 2009	Change from Jul-Dec 2008
Diagnosis				
Mild to Moderate MR	54%	370	3.5	+4%
Profound to Severe MR	12%	264	11.6	+16%
Unspecified MR	7%	37	2.7	+13%
Cerebral Palsy	17%	218	6.7	+6%
Autism	21%	26	0.6	+72%
Epilepsy	19%	254	7.1	-4%

Key Findings:

- Compared to the same period last year, raw mortality rates increased in all diagnosis categories except consumers with epilepsy. These raw rates are not adjusted to reflect differences in risk of mortality by group.
- Mortality rates for consumers with autism increased by 72% compared to the same period last year.
 - Mortality rates among consumers with autism were higher this period compared to the historical average, but the 72% jump reflects an unusually low rate in 2008.

Follow-Up Activities:

- With support from a clinical consultant, Acumen reviewed all mortality incident reports for individuals with autism who died between July 2008 and December 2009.
 - Breaking down the 26 July-December 2009 deaths by cause of death, consumer age, diagnosis, and residence type, we found no unusual trends compared to last period or the same period last year.
 - Reviewing cause of death information over the whole period for individuals diagnosed with autism, we identified 10 cases of deaths related to choking or aspiration. (See page 10 for details on additional follow-up measures.)

More About These Data

The rates shown above are raw rates and do not account for changes in consumer characteristics. Most categories above are not mutually exclusive, as consumers may have more than one diagnosis. Percentages, therefore, do not add up to 100%.

With no spikes during the last six-month period, no remediation activities regarding mortality are planned at the statewide level.

The most recent six-month period saw no statistically significant spikes in statewide mortality rates. As a result, no statewide remediation activities are planned. However, DDS conducts ongoing discovery, monitoring, and system improvement activities. Current activities are described below.

Discovery Activities:

- *Community Care Case File Analysis:* For the next semi-annual mortality report, Acumen will conduct a review of mortality SIRs for deaths that occurred in CCFs between July and January 2009 to determine whether there are any systemic issues that require mitigation activities. (Data analysis can be found on page 8.)
- *Autism Case File Analysis:* Our review of autism deaths identified several cases where we are following up with regional centers for additional information about the death, beyond what is written in the incident report. In addition, we will review a broader set of mortality SIRs to determine the share of deaths associated with choking or aspiration, and linkages between these deaths and specific health conditions and disabilities. As appropriate, we will identify response activities such as SafetyNet content or training materials targeted to these issues. (Data analysis can be found on page 9.)
- *VMRC Case File Review:* We will review VMRC mortality SIRs for FY 2009-2010 to determine whether there are characteristics that explain the high mortality rate when compared to the rest of the state at this RC. Results from the annual review will be summarized in the Annual Report. (Data analysis can be found on page 7.)

Monitoring Activities:

- *Follow-Up on Long-term Increases in Mortality Rates:* Each quarter, Acumen distributes a report to each regional center summarizing trends and changes in mortality rates. These reports identify long-term changes in incident rates as well as monthly spikes. Acumen has developed a method to follow-up with regional centers experiencing long-term increases in mortality rates, analyzing their rates and proposing appropriate follow-up measures.
- *Reporting Back by Regional Centers:* Regional centers experiencing spikes in special incident rates provide structured feedback to DDS describing any follow-up measures taken to address the spike. This information on how regional centers respond to long-term trends may be used to develop strategies on how to mitigate risk to consumers statewide.

System Improvement Activities:

- *Mortality Review Guidelines:* Acumen, in partnership with DDS and the regional centers, has developed a set of Mortality Review Guidelines for California's regional centers. In January 2010, Acumen presented the guidelines in a WebEx meeting attended by staff from all 21 regional centers. The guidelines are now available to the regional centers, along with a separate report describing best practices in mortality reviews from other states. Acumen will also continue to offer technical assistance to regional centers seeking to customize the tools according to their specific needs.